Hospice Experience Survey – Nursing Home Version (65 items)

Please answer the questions in this survey about the care this patient received from this hospice:

[NAME OF HOSPICE LABEL GOES HERE]

All of the questions in the survey will ask about experience with this hospice.

According to the Paperwork Reduction Act of 1995, no persons are required to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is XXX-XXXX. The time required to complete this information collection is estimated to average 15 minutes per response, including the time to review instructions, search existing data resources, gather the data needed, and complete and review the information collection. If you have comments concerning the accuracy of the time estimate(s) or suggestions for improving this form, please write to: CMS, 7500 Security Boulevard, Attn: PRA Reports Clearance Officer, Mail Stop C4-26-05, Baltimore, Maryland 21244-1850.
SURVEY INSTRUCTIONS

• Please give this survey to the person in your household who knows the most about the hospice care received by the person listed on the survey cover letter.

• Answer all the questions by checking the box to the left of your answer.

• You are sometimes told to skip over some questions in this survey. When this happens you will see an arrow with a note that tells you what question to answer next, like this:

  Yes ➔ If Yes, go to Question 1.

  No

THE HOSPICE PATIENT

1. How are you related to the person listed on the survey cover letter?
   
   My spouse or partner
   
   My parent
   
   My mother-in-law or father-in-law
   
   My grandparent
   
   My aunt or uncle
   
   My sister or brother
   
   My child
   
   My friend
   
   Other:
   
   Please print: __________________

2. For this survey, the phrase “family member” refers to the person listed on the survey cover letter. Did your family member receive care from the hospice listed on the survey cover letter?
   
   Yes

   No ➔ If No, please stop and return the survey in the envelope provided.
3. What was the last location in which your family member received care from this hospice?
   Home
   Assisted living facility
   Nursing home
   Hospital
   Hospice facility / hospice house
   Other

**YOUR ROLE**

4. While your family member was in hospice care, how often did you take part in or oversee care for him or her?
   Never ➔ **If Never, please stop and return the survey in the envelope provided.**
   Sometimes
   Usually
   Always

5. Was your family member’s hospice care your first experience with hospice services for a close friend or family member?
   Yes
   No

**STARTING HOSPICE CARE**

For this survey, the [hospice team](#) includes all the nurses, doctors, social workers, chaplains and other people who provided hospice care to your family member. Please do not include hospice volunteers.
6. Did the hospice team explain the kinds of care and services they could give you and your family member?
   Yes, definitely
   Yes, somewhat
   No

7. Did your family member begin getting hospice care too early, at the right time, or too late?
   Too early
   At the right time
   Too late

**YOUR FAMILY MEMBER’S HOSPICE CARE**
As you answer the rest of the questions in this survey, please think only about your family member’s experience with this hospice in the last location in which he or she received hospice care.

8. While your family member was in hospice care, did you need to contact the hospice team during evenings, weekends, or holidays for questions or help with your family member’s care?
   Yes
   No ➔ If No, please go to Question 10.

9. How often did you get the help you needed from the hospice team during evenings, weekends, or holidays?
   Never
   Sometimes
   Usually
   Always
10. While your family member was in hospice care, how often did the nursing home staff and hospice team work well together to care for your family member?
   Never
   Sometimes
   Usually
   Always

11. Personal care needs include bathing, dressing, eating meals and changing bedding. While your family member was in hospice care, how often did your family member get as much help with personal care as he or she needed?
   Never
   Sometimes
   Usually
   Always

12. While your family member was in hospice care, were your family member’s personal care needs ever not taken care of because the nursing home staff expected the hospice team to take care of those needs?
   Yes
   No

13. While your family member was in hospice care, when you or your family member asked for help from the hospice team, how often did you get help as soon as you needed it?
   Never
   Sometimes
   Usually
   Always

14. While your family member was in hospice care, did the hospice team give you and your family member enough privacy?
   Yes, definitely
   Yes, somewhat
   No
15. While your family member was in hospice care, how often did you have a hard time speaking with or understanding members of the hospice team because you spoke different languages?
   Never
   Sometimes
   Usually
   Always

16. While your family member was in hospice care, did the hospice team seem informed and up-to-date about your family member’s condition and care?
   Yes, definitely
   Yes, somewhat
   No

17. While your family member was in hospice care, how often did the hospice team explain things in a way that was easy to understand?
   Never
   Sometimes
   Usually
   Always

18. While your family member was in hospice care, how often did the hospice team keep you informed about your family member’s condition?
   Never
   Sometimes
   Usually
   Always

19. While your family member was in hospice care, how often did anyone from the hospice team give you confusing or contradictory information about your family member’s condition or care?
   Never
   Sometimes
   Usually
   Always
20. While your family member was in hospice care, how often was the information you were given about your family member by the nursing home staff different from the information you were given by the hospice team?
   - Never
   - Sometimes
   - Usually
   - Always

21. While your family member was in hospice care, how often did the hospice team respect your needs and preferences?
   - Never
   - Sometimes
   - Usually
   - Always

22. While your family member was in hospice care, how often did the hospice team spend enough time with your family member?
   - Never
   - Sometimes
   - Usually
   - Always

23. While your family member was in hospice care, how often did the hospice team treat your family member with dignity and respect?
   - Never
   - Sometimes
   - Usually
   - Always
24. While your family member was in hospice care, how often did you feel that the hospice team really cared about your family member?
   - Never
   - Sometimes
   - Usually
   - Always

25. While your family member was in hospice care, did you talk with the hospice team about any problems with your family member’s hospice care?
   - Yes
   - No ➔ If No, please go to Question 28.

26. How often did the hospice team listen carefully to you when you talked about problems with your family member’s hospice care?
   - Never
   - Sometimes
   - Usually
   - Always

27. How often were problems with your family member’s hospice care resolved as soon as you needed?
   - Never
   - Sometimes
   - Usually
   - Always

28. While your family member was in hospice care, did he or she have any pain?
   - Yes
   - No ➔ If No, please go to Question 30.
29. Did your family member get as much help with pain as he or she needed?
   Yes, definitely
   Yes, somewhat
   No

30. While your family member was in hospice care, did he or she receive any pain medicine?
   Yes
   No⇒ If No, please go to Question 33.

31. Did you get the information you needed from the hospice team about your family member’s pain medicine?
   Yes, definitely
   Yes, somewhat
   No

32. Side effects of pain medicine include things like sleepiness. Did any member of the hospice team discuss side effects of pain medicine with you or your family member?
   Yes, definitely
   Yes, somewhat
   No

33. While your family member was in hospice care, did your family member ever have trouble breathing or receive treatment for trouble breathing?
   Yes
   No⇒ If No, please go to Question 36.

34. How often did your family member get the help he or she needed for trouble breathing?
   Never
   Sometimes
   Usually
   Always
35. How often did you get the information you needed from the hospice team about your family member’s trouble breathing?
   Never
   Sometimes
   Usually
   Always

36. While your family member was in hospice care, did your family member ever have trouble with constipation?
   Yes
   No ➔ If No, please go to Question 38.

37. How often did your family member get the help he or she needed for trouble with constipation?
   Never
   Sometimes
   Usually
   Always

38. While your family member was in hospice care, did he or she show any feelings of anxiety or sadness?
   Yes
   No

39. Did your family member need help with feelings of anxiety or sadness?
   Yes
   No ➔ If No, please go to Question 41.

40. How often did your family member receive the help he or she needed from the hospice team for feelings of anxiety or sadness?
   Never
   Sometimes
   Usually
   Always
41. While your family member was in hospice care, did any member of the hospice team discuss your family member’s religious or spiritual beliefs?
   Yes
   No ➔ If No, please go to Question 43.

42. How often did the hospice team treat your family member’s religious or spiritual beliefs with respect?
   Never
   Sometimes
   Usually
   Always

43. Did the hospice team give you as much information as you wanted about what to expect while your family member was dying?
   Yes, definitely
   Yes, somewhat
   No ➔ If No, please go to Question 45.

44. Was the information provided in a way that was easy to understand?
   Yes, definitely
   Yes, somewhat
   No

**YOUR OWN EXPERIENCE WITH HOSPICE**

45. While your family member was in hospice care, how often did the hospice team listen carefully to you?
   Never
   Sometimes
   Usually
   Always
Attachment B

46. While your family member was in hospice care, how often did the hospice team spend enough time with you?
   Never
   Sometimes
   Usually
   Always

47. While your family member was in hospice care, were your religious or spiritual beliefs discussed with any member of the hospice team?
   Yes
   No ➔ If No, please go to Question 50.

48. How often did the hospice team treat your religious or spiritual beliefs with respect?
   Never
   Sometimes
   Usually
   Always

49. Support for religious or spiritual beliefs includes talking, praying, quiet time, or other ways of meeting your religious or spiritual needs. While your family member was in hospice care, how much support for your religious and spiritual beliefs did you get from the hospice team?
   Too little
   Right amount
   Too much

50. While your family member was in hospice care, how much emotional support did you get from the hospice team?
   Too little
   Right amount
   Too much
51. In the weeks after your family member died, how much emotional support did you get from the hospice team?
   Too little
   Right amount
   Too much

**OVERALL RATING OF HOSPICE CARE**
Please answer the following questions about your family member’s care from the hospice named on the cover letter. Do not include care from other hospices in your answers.

52. Using any number from 0 to 10, where 0 is the worst hospice care possible and 10 is the best hospice care possible, what number would you use to rate your family member’s hospice care?
   0  Worst hospice care possible
   1
   2
   3
   4
   5
   6
   7
   8
   9
   10  Best hospice care possible

53. Would you recommend this hospice to your friends and family?
   Definitely no
   Probably no
   Probably yes
   Definitely yes
54. In thinking about your experiences with hospice, was there anything that went especially well or that you wish had gone differently for you and your family member? Please tell us about those experiences.

____________________________________
____________________________________
____________________________________
____________________________________
____________________________________
____________________________________
____________________________________

ABOUT YOUR FAMILY MEMBER
55. What is the highest grade or level of school that your family member completed?
   8th grade or less
   Some high school but did not graduate
   High school graduate or GED
   Some college or 2-year degree
   4-year college graduate
   More than 4-year college degree
   Don’t know

56. Was your family member of Hispanic, Latino/a, or Spanish origin or descent?
   Yes
   No ➔ If No, please go to Question 58.

57. Which group best describes your family member?
   Mexican, Mexican American, Chicano
   Puerto Rican
   Cuban
   Another Hispanic, Latino/a, or Spanish Origin
58. What was your family member’s race? Please mark one or more.
   - White
   - Black or African American
   - American Indian or Alaska Native
   - Asian Indian
   - Chinese
   - Filipino
   - Japanese
   - Korean
   - Vietnamese
   - Other Asian
   - Native Hawaiian
   - Guamanian or Chamorro
   - Samoan
   - Other Pacific Islander

**ABOUT YOU**
59. What is your age?
   - 18 to 24
   - 25 to 34
   - 35 to 44
   - 45 to 54
   - 55 to 64
   - 65 to 74
   - 75 to 84
   - 85 or older

60. Are you male or female?
   - Male
   - Female
61. What is the highest grade or level of school that you have completed?
   8\textsuperscript{th} grade or less
   Some high school but did not graduate
   High school graduate or GED
   Some college or 2-year degree
   4-year college graduate
   More than 4-year college degree
   Don’t know

62. Are you of Hispanic, Latino/a or Spanish origin or descent?
   Yes
   No ➔ If No, please go to Question 64.

63. Which group best describes you?
   Mexican, Mexican American, Chicano/a
   Puerto Rican
   Cuban
   Another Hispanic, Latino/a, or Spanish Origin
64. What is your race? Please mark one or more.
   White
   Black or African American
   American Indian or Alaska Native
   Asian Indian
   Chinese
   Filipino
   Japanese
   Korean
   Vietnamese
   Other Asian
   Native Hawaiian
   Guamanian or Chamorro
   Samoan
   Other Pacific Islander

65. What language do you mainly speak at home?
   English
   Spanish
   Chinese
   Some other language:
   Please print: ________________________

Thank you.
Please return the completed survey in the postage-paid envelope.